

Application for Standard Analytic Files from the Maryland Medical Care Data Base (Non-Governmental Applicants)

Approval Status

Not Started

INSTRUCTIONS

Non-Governmental Applicants may request MD APCD Standard Analytics Files by submitting this completed Application, including attachments and the Data Management Plan. MHCC will review the application package to determine whether the request meets the criteria for data release pursuant to COMAR [10.25.05](#). Review data availability [here](#) then calculate the applicable fees [here](#). Review Important notes:

- Incomplete applications will be returned to the Applicant and the request may be delayed.
- All applications require a non-refundable application fee, payable at the time of submission.
- All application attachments will be incorporated into the Data Use Agreement (DUA) that must be signed prior to any MCDB data being transmitted. A draft DUA will be provided to the applicant after this Application is submitted, so that the Applicant can review the terms and conditions.
- COMAR 10.25.05.07A requires that all completed applications be published on the Commission's website while the application is under review, without the data management plan and security measures.
- Requests that include Maryland Medicaid Managed Care data and Medicare Fee for Service data require special consideration that may increase the review timeline.

[Data Fee Calculator](#) available to estimate the fee for your data sets. The [Data Fee Waiver](#) is available to support those who are unable to access the data for financial hardship. If completing a Data Fee Waiver, please attach it to this application under Attachment H.

This application should only be completed and submitted for Standard Analytic Files. All requests for Custom Data Files should be sent directly to MHCC at mhcc.datarelease@maryland.gov.

List of Required Forms

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PROJECT INFORMATION

Project Title	Collaborative Research: HNDS-R Networks and Health Disparities in Delays in Diagnosis of Medical Conditions with Ambiguous Symptoms
Scheduled Project Start Date	09/16/2024
Scheduled Project End Date	03/14/2028

Project Overview

Intestinal malrotation is a rare birth defect resulting from intestines being incorrectly positioned. The abnormal position of the bowels increases the likelihood of an intestinal twisting, which can be fatal. Prompt diagnosis of intestinal malrotation is critical for saving lives and preventing long-term health problems and yet research shows that misdiagnosis and diagnostic delays are common. This project will use MCBBD_APCD data to statistically examine factors that affect time to diagnosis for intestinal malrotation and will also examine medical trajectories before, during, and after diagnosis (e.g., common misdiagnoses, outcomes of diagnoses and procedures, what treatments are used, their effectiveness and consequences, comorbid conditions, and differences between pediatric and adult patients) and how they compare to a general baseline population without the condition. We will examine whether marginalized people are more likely to experience delays in diagnosis, poorer health outcomes, and different treatment trajectories and whether patient-provider networks (e.g., ties to other providers through patients) affect these outcomes.

Applicant

(Agency, Academic Institution, Research Organization, Company, Individual, etc.)

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City		State		Zip code	

Principal Investigator/Project Manager

(Individual responsible for the research team using the data)

Name	<u>Katie</u>	<u>Corcoran</u>
First Name	Last Name	

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Type a label	

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State

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Data Custodian

(person responsible for receiving, organizing, storing, and archiving data)

Name Wes Kimble

First Name Last Name

Title Director of Research Data Analytics

Organization/Company (if different from Applicant) West Virginia University Health Sciences Center

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Relationship to Applicant (e.g., Contractor)

Director of Research Data Analytics for WVCTSI, Corcoran is a member of WVCTSI

Relationship

Project Contact

(person responsible for all communications with MHCC)

Name Katie Corcoran

First Name Last Name

Title Professor of Sociology

Type a label

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City/Town Morgantown State WV

City State

Project Purpose

Zip Code 26505

ATTACHMENT A: PROJECT SCOPE

a. Describe the specific research question(s) you are trying to answer or problem(s) you are trying to solve with the requested data or describe the intended product or report that will be derived from the requested data. If a research project, please list each individual question or aim of the analysis.

What factors affect time till diagnosis of intestinal malrotation? Does marginalized status (e.g., women, those who live in rural areas, and racially/ethnically minoritized patients) and patient-physician networks (e.g., providers are connected to the extent that they share patients) affect time till diagnosis and medical trajectories (e.g., treatment options, procedures performed, and long-term outcomes) of patients with intestinal malrotation? What are common misdiagnoses? What diagnosed symptoms or tests/procedures accelerate or delay time till diagnosis? How does a delay in diagnosis affect long-term health outcomes? What are the medical trajectories before, during and after diagnosis of intestinal malrotation? What symptoms continue after surgery, how long do they continue, and what treatments are used to manage them? What procedures and treatments are used before, during, and after diagnosis? How effective are they and what are their consequences? What other medical conditions are more likely to occur with intestinal malrotation and do they affect time till diagnosis and long-term outcomes? Do medical trajectories and time till diagnosis differ based on age at diagnosis (child versus adult)? How many and what types of physicians/specialists have to be seen before a diagnosis is made and how many are seen after a diagnosis to manage continuing symptoms? How do the outcomes and medical trajectories of individuals diagnosed with intestinal malrotation compare to a baseline general population of patients that have not been diagnosed with intestinal malrotation?

b. Briefly describe the purpose(s) for which MD APCD data is sought. Use quantitative indicators of public health importance where possible. For example: variation in costs of care; rates of under or over service utilization; health system performance measures; the effect of public health initiatives, health insurance, etc.

The purpose for which MD APCD data is sought is to identify factors associated with delays in diagnosis and long-term health outcomes in intestinal malrotation patients in order to inform future interventions to reduce morbidity and mortality. Intestinal malrotation is a dangerous rare condition that is not visible externally. When it is diagnosed in babies and children it is treated as an emergency. A population-based study identified the first-year mortality rate at 15.8%. Additionally, the condition increases the likelihood of a life-threatening condition (midgut volvulus) where the intestines twist, which is estimated to have a mortality rate of up to 47%. When diagnosed promptly the condition is treatable.

c. Explain in detail how the planned project that will use MD APCD data is in the public interest and give specific examples of how the project will serve the public interest.

Rare diseases, because they are rare, do not receive much attention or research. Rare disease patients and their family deserve research on their condition that could have the potential to improve their quality of life or even save their life. This project is a part of a larger community-engaged research project on intestinal malrotation where we conducted focus groups with community members to identify their research interests. Delays in diagnosis and long-term health outcomes were the two most common topics identified that they seek research on and that they said would be the most impactful for their quality of life. Additionally, the findings from this project have the potential to identify broader factors, such as the structure of patient-physician networks, that affect delays in diagnosis that could be applied to other conditions. Many patients with intestinal malrotation and caregivers of patients state that doctors don't

recognize their symptoms as connected to malrotation and don't have the necessary knowledge to manage or treat their symptoms. Doctors we have interviewed also identify lacking the knowledge to make informed healthcare decisions for their patients due to a lack of published research. This project will respond to the needs of patients, caregivers, and doctors by publishing research on intestinal malrotation that can inform their future healthcare decisions and options.

d. Explain why the planned project could not be practicably conducted without access to and use of protected health information.

Our project will be investigating delays in diagnosis of intestinal malrotation and long-term medical trajectories, including tests, procedures, and treatments. We need to know the date of the intestinal malrotation diagnosis and the date the symptoms were first diagnosed in order to measure how long it took from when the symptoms were first diagnosed until the condition itself was diagnosed. We will also need the subsequent dates for diagnosed symptoms, other diagnosed conditions, tests, procedures, and treatments in order to create a timeline/trajectory and determine how the timing of particular tests, procedures, treatments, and diagnoses affect long-term outcomes. We need to know zip code in order to merge county level data on healthcare access and social disadvantage into the data.

e. Explain why the planned project could not be practicably conducted without waiving any individual authorization required by 45 CFR § 164.508.

Because the project examines a rare disease for which a small percentage of the population has and because it will examine medical trajectories over time, it requires large-scale, longitudinal data. The MBD-APCD is ideal for this purpose. Since the MBD-APCD has already been collected, it is not practical to obtain individual authorization.

Project Methodology

a. Describe the project methodology, including project objectives, relevant study questions, analysis methods, software, groupers, and other analytical tools

The objectives of the project are to identify factors (e.g., patient, physician, or geographical area factors) that affect time till diagnosis and medical trajectories (e.g., treatment options, procedures performed, short-term and long-term outcomes, and specialty visits) and whether this varies by age at diagnosis (child versus adult) and socio-demographic characteristics. For medical trajectories we will also compare intestinal malrotation patients with a control group who does not have intestinal malrotation.

Protocol: We will conduct a retrospective cohort analysis of Maryland individuals with claims in the MBD-APCD diagnosed with intestinal malrotation and a control group of Maryland individuals with claims in the MBD-APCD who have not been diagnosed with intestinal malrotation. Maryland has a diverse population, which is ideal for examining associations between the outcomes of interest and socio-demographic characteristics. Although intestinal malrotation is rare, it is estimated to occur in 1 in 200 to 1 in 500 live births. Because of this, with multiple years of data, the MBD-APCD will have a sufficient sample size.

Relevant study questions: What factors affect time till diagnosis of intestinal malrotation? Does marginalized status (e.g., women, those who live in rural areas, and racially/ethnically minoritized patients) and physician networks (e.g., physicians are connected to the extent that they share patients) affect time till diagnosis and medical trajectories (e.g., treatment options, procedures performed, and long-term outcomes) of patients with intestinal malrotation? What are common misdiagnoses? What diagnosed symptoms or tests/procedures accelerate or delay time till diagnosis? What factors affect short and long-term health outcomes for patients with intestinal malrotation including morbidity and in-patient mortality and how do they compare to a control group of patients without intestinal malrotation? What are the medical trajectories before, during and after diagnosis of intestinal malrotation? What symptoms continue after surgery, how long do they continue, and what treatments are used to manage them? What procedures and treatments are used before, during, and after diagnosis? How effective are they and what are their consequences? What other diagnosed medical conditions are more likely to occur with intestinal malrotation compared to a control group and do those conditions affect time till diagnosis and long-term outcomes? Do medical trajectories and time till diagnosis differ based on age at diagnosis (child versus adult)? How many and what types of physicians/specialists have to be seen before a diagnosis is made and how many are seen after a diagnosis to manage continuing symptoms?

Analysis methods:

Cohort identification: Intestinal malrotation patients will be identified based ICD diagnosis codes (ICD 9: 751.4; ICD 10: Q433). The control group will be identified based on never having one of those diagnosis codes in their claims.

Time till diagnosis of intestinal malrotation:

From the first instance of a diagnosis of intestinal malrotation in which a claim reports a diagnosis code of ICD 9: 751.4 or ICD 10: Q43.3, the patient is classified as having intestinal malrotation. The date of service in which the patient received the diagnosis will represent the date of diagnosis of intestinal malrotation. Although patients are born with intestinal malrotation, in order to capture true delays in diagnosis, there must be an opportunity for the physician to diagnosis intestinal malrotation which requires symptoms, except in rare cases where the patient underwent imaging or surgery for other medical conditions (we will identify such testing or procedures using ICD codes). Following Roll's (2012) study on delays in diagnosis for the rare condition Marfan Syndrome, we will use the onset of symptoms typically associated with intestinal malrotation to set time zero. If the patient had any of the following diagnoses using ICD codes, it is assumed that intestinal malrotation could have been diagnosed but was not: vomiting, nausea, abdominal distension, diarrhea, blood in feces, bilious vomiting, vomiting blood, abdominal pain, stomach pain, gastro-esophageal reflux disease (GERD), cyclic vomiting syndrome, failure to thrive, loss of appetite, Crohn's disease, Irritable Bowel Syndrome (IBS), gastroenteritis, and abdominal migraines. We will create a variable that represents a count of the number of days between time zero (the service in which the diagnosed symptoms/conditions first appear on a claim) to when the patient received a diagnosis of intestinal malrotation.

Marginalized status:

We will use race (not white), ethnicity (Hispanic), preferred spoken language (not English), sex (female), and residence location (linked data will provide information on measures of poverty and rural status) to capture marginalized status.

Diagnosed symptoms, conditions, testing, procedure, and medication codes:

The following will be used to look at which diagnosed symptoms, conditions, testing, and procedures accelerate or delay time till diagnosis as well as to examine medical trajectories over time (short-term and long-term health outcomes, comorbid conditions, and treatments). Symptoms/signs involving the digestive system/abdomen (ICD-10 R10-R19), symptoms concerning food & fluid intake (R63), lack of expected normal physiological development (R62), diseases of the digestive system (K00-K95), malnutrition (E40-E46), volvulus (560.2), diagnostic radiology procedures of the abdomen, and surgical procedures of the digestive system, intestines, and abdomen (5495; 5459; 4719; 4681; 4682; 0DTJ0ZZ; 0DS90ZZ; 4709; 0DN90ZZ; 0DN80ZZ; 5411; 0DSH0ZZ; 0DSA0ZZ; 0DSB0ZZ; 0DSK0ZZ; 0DNE0ZZ; 0DNW0ZZ; 4680; 0DSL0ZZ; 0DNH0ZZ; 0DNA0ZZ; 0DNB0ZZ; 0DSM0ZZ; 0DSN0ZZ; 0DNK0ZZ; 0DNF0ZZ; 0DNL0ZZ; 0DNM0ZZ; 0DNC0ZZ; 4663; 4562; 4591; 4639; 4610; 4620; 0DBB0ZZ; 4593; 4573; 0DB80ZZ; 4572; 0DBA0ZZ; 4561; 4621; 4579; 4611; 4601; 0DB90ZZ; 4623; 4603; 4575; 4590; 0DBH0ZZ; 0DTH0ZZ; 4576; 4594; 4563; 0DTB0ZZ; 0DTP0ZZ; 4574; 4582; 0DBE0ZZ; 0DBJ0ZZ; 0DBL0ZZ; 0DBM0ZZ; 0DBN0ZZ; 0DTA0ZZ; 4571; 0DBC0ZZ; 0DNG0ZZ; 0DNN0ZZ; 0DTF0ZZ; 0DB87ZZ; 0DBK0ZZ; 0DT80ZZ; 0DT90ZZ; 0DTC0ZZ; 0DTE0ZZ; 0DTK0ZZ; 0DTL0ZZ; 0DTS0ZZ; 0DTG0ZZ; 0DTN0ZZ; 0D1K0Z4; 0D1K0Z4; 0D1H0JK; 0D1H0JK; 0D1H0J4; 0D1H0Z4; 0D1M0Z4; 0D190ZB; 0D190ZB; 0D190ZA; 0D1B0ZK; 0D1B0ZK; 0D1B07H; 0D1B07H; 0D1B0ZH; 0D1B0J4; 0D1B0J4; 0D1B0Z4; 0D1B0ZB; 0D1B0ZL; 0D1B0ZL; 0D1A0Z4; 0D1A0ZB; 0D1A0ZA; 0D1L0Z4; 0D1L0ZM; 0D1L0ZM; 0D9H0ZZ; 0D9B0ZZ; 0D9A00Z; 0D980ZZ; 0DBH0ZX). Additional codes will be identified inductively from the data.

Linked data from the AMA Physician Masterfile:

We will use this data to identify physician gender, age, specialty, medical school graduation year, credentials, and location of work. Number of years since graduating medical school is often used as a proxy for medical knowledge. Whether the physician is a specialist in a specialty knowledgeable about intestinal malrotation may affect time till diagnosis. Some research suggests that socio-demographic matching of physician and patient, such as by gender, may produce better health outcomes.

Variables: Physician zip code, county, birth date, birth city, state, and country, sex, presumed dead, license state and year, license hospital year and state, license alt office year and state, present employment, primary and secondary specialty, primary type of practice, major professional activity, hospital ID, hospital hours, physician recognition award, expiration data of PRA certificate, graduate medical training, dates of

medical training, year of training in current program, cumulative year of training, first and second specialty of physician's graduate training, medical training institution code and school ID, medical school year of graduate, number of offices, office address including state and zip code, trained in the US, residency training state, medical school state, dates of residency, and core based statistical area and division.

Linked data from SDOH (at zip code and county levels):

Location level factors could influence time till diagnosis and future medical trajectories due to access to healthcare, social vulnerability index, poverty rate, and physical infrastructure context. Variables: demographics, living conditions, disability immigration, socioeconomic disadvantage indices, segregation, income, employment, poverty, attainment, school system, educational funding, literacy, numeracy, housing, transportation, migration, internet connectivity, environment, industry composition, social services, food access, access to exercise, crime, health insurance status, characteristics of health care providers, characteristics of health care facilities, distance to provider, utilization and costs, health behaviors, health outcomes, and health care quality.

Network measures:

For each intestinal malrotation patient, we will identify all their providers using their NPIs. For each of these providers, we will identify all of their patients, not just those diagnosed with intestinal malrotation. For all of these patients (i.e., those patients that do not have intestinal malrotation but are seen by a provider who also sees an intestinal malrotation patient), we will identify all of their providers and the patients of those providers. This represents the entire network of providers that see intestinal malrotation patients, since it includes all the providers of their patients, even the ones without intestinal malrotation. We will also create network measures for our control group based on their providers, the patients of their providers, and the providers of those patients. In order to create the entire network of patients and providers for those patients and providers specified in the claims, the minimum necessary data for this project is the entire dataset for the requested. This is important, because even though intestinal malrotation is a rare condition and will have a relatively smaller number of cases, to create the network it requires the standard analytic dataset. Additionally, we will compare the outcomes to a general baseline population (control group) never diagnosed with intestinal malrotation.

The patient-provider network we will create is a two-mode network—a network with two different types of nodes in which nodes can only be connected to nodes of a different type. Providers and patients are different types of nodes. A connection between a patient and a provider represents any encounter/service between a provider and a patient for which there is a medical claim. Connections will be added over time through additional encounters/services but not removed as previous encounters/services are a part of the patient's medical history and may influence future encounters with new providers (Groopman 2008; Kliegman et al. 2017; Simacek 2018). We will estimate network measures for each of these networks that will then be attributed to the corresponding patient. We provide the technical description of these measure below.

Two-mode Degree Centrality: Two-mode degree centrality is a measure of the amount of information a patient has access to. Two-mode degree centrality is measured as the number of providers that a given patient i sees. The more patient i is connected to different providers, the more likely she will be exposed to more information and diagnoses; thus, increasing her chances of receiving a correct diagnosis. We will also create a two-mode degree centrality measure that weights the connections by physician tenure (i.e., number of years since graduating medical school) and another measure that only counts ties to specialists. We will also explore what type of specialist matters by examining ties to gastroenterologists, which is the specialty associated with gastrointestinal issues.

Two-mode Bridging: According to Burt (1995), ties that bridge structural holes (i.e., holes in the network where there are few ties) facilitate the flow of new information across different regions or communities in the network. A patient's bridging capacity can be measured via two-mode effective size (Burchard and Cornwell 2018), which is equal to the size of a patient i 's network minus the two-mode redundancy of i 's network. Put simply, patient i 's network is said to be two-mode redundant the more it looks like a cluster, that is, if her provider(s) happen to see the same patients.

Two-mode Homophily: We will measure homophily based on both the endogenous characteristics of the patient-provider network (i.e., the patterns of connections), as well as the exogenous (i.e., non-network) characteristics of the providers and their patients. In terms of the former, we will use provider gender and

age. We will also use the race, age, and gender of patients to capture homophily in patient characteristics across the two-mode network. Two-mode homophily can be measured via 4-cycles (Fujimoto, Snijders, and Valente 2018). For example, assuming patients i and j share providers a and b, a homophilous 4-cycle is said to exist if patients j and k also happen to share the same exogenous characteristic (e.g., ethnicity)

Methods and work plan:

We will use event history analysis to test our predictors on time to diagnosis of intestinal malrotation where time refers to number of days. Network measures, misdiagnoses, and procedures will be time varying and updated for each time unit based on the date of the service, misdiagnosis, and/or procedure occurred. For analyses related to medical trajectories we will use appropriate regression models depending on the form of the outcome variable (e.g., logit for binary variables, ordinary linear regression for continuous normally distributed variables, poisson or negative binomial for count models, etc).

We will examine the data for the degree of missingness and use data imputation if necessary.

Software:

STATA [StataCorp. 2023. Stata Statistical Software: Release 17. College Station, TX: StataCorp LLC.]

SAS [SAS Institute Inc 2013. SAS 9.4. Cary, NC: SAS Institute Inc]

R [R Core Team 2023. R: A Language and environment for statistical computing. R Foundation for Statistical Computing. Vienna, Austria. URL: <http://www.R-project.org/>].

b. If required by your funding source or home institution to obtain Institutional Review Board review for your project, provide the information regarding the IRB approval below and attach a copy of the current IRB approval on tab "Attachment H".

IRB Approval End Date

03-14-2028

Date

IRB Name and Location

West Virginia University, Morgantown, WV

blanks

Publication and Dissemination

a. Do you anticipate that the results of your analysis will be published or made publicly available? If yes, how do you intend to disseminate the results of the study (e.g., publication in a professional journal, poster presentation, newsletter, web page, seminar, conference, statistical tabulation, etc.)?

Yes. We intend to disseminate the results of the study through conference presentations, poster presentations, publication in professional journals, books, seminars or workshops, through social media, in our teaching, and through reports on a website or through social media.

b. All public displays of MD APCD data, regardless of the medium, must comply with MD APCD's cell size suppression policy, as set forth in the Data Use Agreement. Describe how you will ensure that any public display will suppress every cell containing less than 11 observations and suppress percentages or other mathematical formulas that result in the display of every cell with less than 11 observations.

Results will be reported in the aggregate and any cell with less than 11 observations in the aggregate will not be reported and will be suppressed.

c. Identify the lowest geographical level of analysis of data you will present for publication or presentation (e.g., state level, city/town level, zip code level, etc.). Will maps be presented? What methods will be used to ensure that individuals cannot be re-identified in this publication

or presentation?

While we will use zip codes in the analysis, we will not present data at that level. The lowest geographical level of analysis of data we will present will be the county level. However, we will suppress any counties with less than 11 observations and data will be presented in the aggregate to ensure that individuals cannot be re-identified. Since we are combining multiple years of data, there should be sufficient observations to present data at the county level.

If you answer "yes" to any of the following questions, describe the types of products, software, services, or tools and what the corresponding fees will be for such products, software, services, or tools.

a. Will the MD APCD data be used for consulting purposes?

No.

b. Will report(s), website(s), or statistical tabulation(s) using MD APCD data be shared or sold?

Reports and statistical tabulations using MD APCD data will be shared with the patient and academic communities through websites, social media, and email. Nothing will be sold.

c. Will a software product using MD APCD data be shared or sold?

No.

d. Will MD APCD data be used as input to develop a product (i.e., severity index tool, a risk adjustment tool, a reference tool, etc.)?

No.

e. Will MD APCD data be sold or shared in any format not noted above? If yes, in what format and who are the purchasers of the data?

No.

f. Will the project result in disclosing MD APCD data, or any data derived or extracted from such data, in any paper, report, website, a statistical tabulation, seminar, or another setting that is not disseminated to the public?

No.

g. Will the results from the project be used for the purpose of price transparency?

No.

h. Will health care providers be individually identified? If yes, describe your protocol for informing health care providers prior to publication of this data/report.

Health care providers may be individually identified through the data analysis process but this information will not be published or presented.

Funding Sources

a. What is the source of funding that supports this project? Provide detailed information about

potential and actual sources.

National Science Foundation

b. Describe any data sharing or other requirements imposed by the above funding sources as a condition for receipt of funding?

Our data management plan does not require us to share the data. We will share statistical code/syntax we use to run particular analyses but not the data itself.

c. Please upload documentation that includes grant number, a budget, and any information that shows the available funding for this project.



NSF Award Search_Award _pdf

Data Security

a. Explain how your use of data will involve no more than a minimal risk to the privacy of individuals. As part of your response, please address how you will protect the data from improper use or disclosure and assure that the data will not be reused or disclosed to any other person or entity, except as required by law, for authorized oversight of the research for which the data was requested, or for other research for which the use or disclosure of PHI would be permitted under 45 CFR 164.512(i)(2)(ii).

The project was approved by West Virginia University's IRB as no more than minimal risk. We will follow the data cell suppression policy (no more than 11 observations) and will only report data in the aggregate, which presents no more than minimal risk to the privacy of individuals. The data will be kept on a secure server per the data management plans and only authorized users will have access too it. All members of the research team have human ethics and PHI training.

ATTACHMENT B: MD APCD DATASET REQUESTED

The MD APCD contains fully processed records for eligibility and professional, institutional, and pharmacy claims for privately fully-insured and non-ERISA self-insured health insurance plans licensed in Maryland for both in-state and out-of-state covered members. Please review the [data dictionary](#) before completing this section. Calendar years 2010-2021 are currently available.

MD APCD Data

Dictionary: https://mhcc.maryland.gov/mhcc/pages/apcd/apcd_data_release/documents/User_Manual_2019_V1_Codebook.pdf

Standard Analytic Files: Formerly known as the Standard Data Extract. The Standard Analytics Files contain four fixed (i.e., non-customizable) files- the Medicaid Eligibility File, the Professional Services File, and the Pharmacy File. Information about the specific data elements provided within each of the four files can be found in the Data Dictionary. This data set does not include data from Medicare.

Custom Data Set: A custom data extract can be created based on criteria provided by an Applicant if the data are deemed the minimum amount necessary for an Applicant's proposed use of the data and includes:

a. Indirect individual identifiers that cannot be used to identify individuals when combined with other information or data; or

b. Aggregate, summary data in which the risk of identifying individuals is minimal.

Custom Data Sets can also include requests for linkage across data sets.

This application should only be completed and submitted for Standard Analytic Files. All requests for Custom Data Files should be sent directly to MHCC at mhcc.datarelease@maryland.gov.

Which MD APCD files are you requesting? Provide a brief justification (1-3 sentences) for each one. Specifically address why this is the minimum necessary data to accomplish the study.

Institutional Claims

Commercial

Years of Institutional Claims (Specify for Medicaid and Commercial if different)

2016-2021

Justification for Requesting Institutional Claims

The MCDB institutional claims are needed to capture hospitalizations before, during or after diagnosis of intestinal malrotation patients as well as clinical services they received in inpatient, outpatient, and ED settings. They are also needed to identify the attending practitioner NPI and operating practitioner NPI in order to create a patient-sharing physician network.

Professional Claims

Commercial

Years of Professional Claims (Specify Medicaid and Commercial if different)

2016-2021

Justification for Requesting Professional Claims

The MCDB professional claims are needed to identify any diagnoses of intestinal malrotation (based on ICD diagnosis codes) as well as diagnosed symptoms before and after the diagnosis. The professional claims are also needed to identify the practitioner NPI used for billing in order to create the patient-sharing physician networks.

Pharmacy Claims

Commercial

Years for Pharmacy Claims (Specify Medicaid and Commercial if different)

2016-2021

Justification for Requesting Pharmacy Claims

The MCDB pharmacy claims are needed to identify which types of pharmacological treatments are used to manage and treat intestinal malrotation and to identify the prescribing provider NPI to create the patient-sharing physician networks.

Member Eligibility

Commercial

Years for Member Eligibility (Specify Medicaid and Commercial if different)

2016-2021

Justification for Requesting Member Eligibility

The MCDB member eligibility dataset is needed for the demographic characteristics of individuals diagnosed with intestinal malrotation.

ATTACHMENT C: ADDITIONAL DATA SOURCES AND LINKAGE

1. Maryland Medicaid Managed Care Data

Applications for access to Medicaid Managed Care data are sent to the Maryland Medicaid Administration for review and comment. The fields available on the Medicaid MCO data sets have been aligned with Maryland APCD fields to the extent greatest possible. Medicaid Fee for Service data sets are not available.

a. Are you requesting Medicaid data?

b. Do you intend to merge or link Maryland APCD data with Medicaid data?

2. Medicare Data

If requesting Medicare data, the request will be reviewed in accordance with the [State Agency DUA](#) and [CMS State Data Request Memo](#). Per the CMS State Data Request Memo, researchers that are not doing work under the direction of the state will need to request the data through the current CMS research request process. Additionally, researchers in states that receive data under this process for studies that are under the direction of, and are partially funded by a state, will still be required to request the data through the current CMS research request process for other studies that are conducted under different authorities or funding.

a. Are you requesting Medicare Data?

3. Other Linkages

a. Do you intend to merge or link Maryland APCD Data with other data?

i. What are the files to be linked?

Yes, we will link to data from American Medical Association (AMA) Physician Masterfile data files, which will provide additional information on providers. We will also link with the the Agency for Healthcare Research and Quality publicly available Social Determinants of Health (SDOH) Database.

ii. Why is this linkage needed?

The study will look at how physician characteristics may affect patient outcomes. Physician characteristic data will come from the AMA Physician Masterfile. Health outcomes can be affected by the broader social, economic, and healthcare context. To measure the broader context, we will use data from the SDOH.

b. Which Maryland APCD data elements will be linked to the data elements in the external file?

We will merge the MCBDB data with the AMA Physician Masterfile data using NPI numbers for physicians and facilities. We will merge MCBDB data with the SDOH using zip codes and/or counties. This will create one combined file with data elements from the files.

c. What methodology or algorithm will be used to create this match? If you intend to create a unique algorithm, describe how it will link each dataset.

We will match data from the AMA Physician Masterfile with the MCBDB using NPIs for physicians and facilities. We will match data elements from SDOH with the MCBDB using zip codes and/or counties.

d. What variables from each of the source files will be included in the final linked analytic file?

From the AMA file: Physician zip code, county, birth date, birth city, state, and country, sex, presumed dead, license state and year, license hospital year and state, license alt office year and state, present employment, primary and secondary specialty, primary type of practice, major professional activity, hospital ID, hospital hours, physician recognition award, expiration data of PRA certificate, graduate medical training, dates of medical training, year of training in current program, cumulative year of training,